

Status Report

THE NEWSLETTER OF THE PREMIER'S COUNCIL ON THE STATUS OF PERSONS WITH DISABILITIES

NOVEMBER 1997



Access to Information

Disabled Score Landmark Supreme Court Victory

Canada's top court has ruled that the B.C. government—and by implication other provinces—has to pay for sign language interpreters when required by deaf people in hospital or at doctors' offices.

The sweeping 9-0 ruling provides all people with disabilities with a powerful precedent to use in the legal struggle to remove barriers preventing full participation.

On October 10, the Supreme Court said B.C.'s refusal to pick up the "relatively insignificant" \$150,000 yearly cost for interpretation violates the constitutional rights of deaf people to equal benefit of the law guaranteed by the Charter of Rights and

Freedoms. The court also said that governments are required by the charter to take reasonable positive steps to ensure that disadvantaged groups are able to benefit equally from services offered to the general public, even if those services are privatized.

"It is an unfortunate truth that the history of disabled persons in Canada is one of exclusion and marginalization," wrote Mr. Justice Gerard La Forest in his ruling.

The Supreme Court challenge was brought by Linda Warren, a B.C. woman who is deaf. In 1990, Warren gave birth to premature twins in terror because she was unable to communicate with doctors and

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nurses. The B.C. government refused to pay for translators, claiming it would stretch resources and provide a precedent for the funding of similar services for non-English-speaking immigrants.

The Alberta government already pays for sign language interpreters in hospitals for deaf people who are referred by doctors. ♦

Sledges in Schools Program Offers Thrills on Ice

The Paralympic Sports Association and the Northern Alberta Crippled Children's Fund have teamed up to offer the Sledges in School Project.

Through the program, sledges will be loaned to Edmonton and area schools for use in physical education skating programs by students who are unable to use stand-up skates.

"The objective of this project is to open doors and enhance the independence of school-aged children and youth who are unable to participate in regular ice skating programs," says Nadine Hines, Program Coordinator.

"This will increase the awareness of children and young adults in

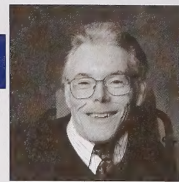
the school system as to the abilities of persons with a disability, through the medium of sport and recreation."



Sledges have become increasingly popular in recent years with people who have mobility impairments—particularly for use in the game of sledge hockey. Sledge hockey is much like its stand-up counterpart, except there are certain sledge and stick inflections.

Paralympic Sports Association offers a number of sledge hockey programs. For more information on the Sledges in School Project or sledge

hockey, contact PSA at 439-8687. ♦



Growth Summit Sets Stage for Alberta in the 21st Century

Gary McPherson, L.L.D. (Honourary)

Many people, knowing I was involved from the ground floor, have asked me for my impressions of the recently held Growth Summit. From my perspective as a planner and a participant, it was a fascinating and dynamic gathering of public opinion.

I believe the resulting recommendations will be incredibly useful in determining directions for our province. The process itself was equally valuable. At the very least, it could serve as a model for future public involvement in government—and perhaps it will permanently change the way government gathers input and information.

First, an overview of what resulted from the Summit. As you probably know, six sectors were represented: energy, business & industry, agriculture, government, the “social economy”, and a loosely allied group that included municipalities, academic institutions, services, hospitals and other—MASH for short. The Alberta Federation of Labour chose not to participate; representatives of other unions were sought instead to provide input from this sector.

Over the course of the Summit, the 100 or so participants produced 243 recommendations. With apologies for omissions, here’s a quick summary by sector.

Energy and business & industry representatives were aligned in their thinking. Their recommendations largely dealt with eliminating taxes and regulations that hindered economic growth and free enterprise.

Similarly, the agriculture sector focused on the need for elimination of regulation that hindered its ability to be competitive on the world stage and expand its markets. Agriculture emphasized the need for government and public investment to enhance its world marketability.

Government representatives issued a warning of a crumbling public service. Aging of government employees and salaries

that aren’t competitive with the private sector were among the problems reported. The fact that there are currently three vacant deputy minister positions is indicative of this problem. Representatives emphasized that the public service must be rebuilt and revitalized to regain public confidence.

Representatives of the social economy sector maintained that social and economic interests are indivisible. This sector maintained that a balance must be continually

“In short, the Summit was a wide-open process that gathered and filtered an incredible amount of public feedback. In my mind, it has planted the seeds of democratic change.”

sought between profits and people. Profits must support people, and people—particularly vulnerable people, such as children and disadvantaged groups—must be the priority. In turn, an enhanced social system will ensure continued economic growth as the province is viewed as a desirable place to do business and live.

Finally, the MASH sector focused on the looming problem of a burgeoning invisible deficit—the crumbling of physical infrastructures, such as highways, and of human infrastructures, such as healthcare. Like the social economy sector, this sector stressed the need to balance economic growth with investments that yield improved quality of life for all citizens of our province.

What will become of the 243 individual recommendations? Will they go anywhere?

Or will they form the basis of a new government platform or vision as the new millennium approaches?

Cautiously, I suggest the answer lies closer to the latter. Why? Because of the process.

Co-chairs Premier Klein and former Liberal finance critic Mike Percy, now the Dean of Business at the U of A, are to be commended for ensuring the Growth Summit was entirely transparent—that is, the entire proceedings were wide open to local and national media and public scrutiny. Not only were there no closed doors, every minute of the Growth Summit was transmitted on live television across the province.

It was truly one of the most open, inclusive processes I’ve ever been witness to. It was anything but the elitist event that skeptics denounced beforehand. Unlike the roundtable discussions of recent years, government had no involvement in selecting the primary representatives. And remember, there were some 35 mini-Summits and over 4,000 submissions from individuals and groups, all of which were fed into the process. Additionally, all information was available at the Summit’s website, and a great deal of feedback was also obtained via the Internet.

In short, the Summit was a wide-open process that gathered and filtered an incredible amount of public feedback. In my mind, it has planted the seeds of democratic change. In the future, it will be looked to as a model for gathering and filtering public opinion.

In this day and age, there are increasing expectations of responsible government and public accountability. If decision-makers fail to listen to recommendations made at the Growth Summit, they do so at their own peril. I believe that failing to listen will result in public criticism. And the public will

have an expectation of similar processes in the future. With an ever-expanding array of communication technology—consider videoconferencing's potential—on the horizon, the implication for democracy is that this type of consultation will become routine.

The process also resulted in revelations for many of the representatives, who came from diverse backgrounds and participated in a spirit of cooperation and with a noticeable absence of political posturing. Many spoke of developing a new understanding of the various positions represented.

For example, the agriculture sector is strongly in favour of right-to-work legislation. Labour is strongly opposed. Prior to the Summit, it's doubtful that representatives of the two sides ever had an opportunity to explain their rationale: right-to-work, for agriculture, represents avoiding the waste of their crops during a strike; for labour, right-to-work signals a decrease in the power of unions and an undermining of the collective bargaining process.

While the two sectors are undoubtedly far from consensus, each reports being more

open-minded and receptive due to the opportunity of hearing, in person, the rationale of the other. Likewise, business leaders openly admitted they had increased their understanding of social concerns.

As for Albertans with disabilities, both results and process bode well. A great deal of what people with disabilities asked for was included in the final recommendations. Naturally, at this early stage, some of the specifics have been lost. But remember—this is just a beginning.

To repeat, I believe the process will become commonplace. So people with disabilities and their respective organizations must learn to take an active, ongoing role. The Coalition of Provincial Disability Organizations, formed this past July, is to be particularly commended for its efforts. Composed of some 25 large organizations, this Coalition presented a thoughtful discussion paper to Summit participants. I'm heartened by this Coalition's ability to set aside differences and strive for a common cause. I am hopeful that it will view all future events of this nature as important opportunities and

remain articulate, consistent and clear in its efforts.

Make no mistake—disability is back on the table.

As an aside, I'm also proud to note that organizers admitted borrowing heavily from this Council's discussion papers, which have been produced steadily for the past three years. It's a clear indication that the Council's efforts have been useful—even instrumental—in charting new directions for Alberta.

On a final note, I would like to take this opportunity to welcome two new staff members to our Council. Elaine Chapelle, Ph.D., has assumed the position of Acting Executive Director. Mikaline Anderson assumes the position of Information Officer. Elaine and Mikaline join Christine Gilliard, Administrative Assistant.

I'm pleased to have these qualified individuals on our team, and I'm sure they, along with our appointed Members, will help ensure our Council continues to contribute to the well-being of our province and its citizens with disabilities. ♦

Message from Elaine Chapelle, Acting Executive Director

I am delighted to be joining the team at the Premier's Council on the Status of Persons with Disabilities, as Acting Executive Director.

Although I have some personal and professional perspectives regarding issues faced by persons with disabilities, I don't pretend to be an expert at understanding all of the issues. However, I bring a strong value base and commitment to learning about and helping ensure that people with disabilities' interests and needs are heard and met by all levels of government.

For the past six years, I worked as a senior manager in the Special Education Branch of Alberta Education. In addition to developing policies and procedures related to services for students with special needs in schools, my work focused on improving the cross-department coordination of services for persons with disabilities (including the Community Supports Model). I also have experience as a teacher and counsellor in the public school system, and as an instructor at both university and college levels. I have a doctorate in Educational Psychology.

While I was with the Special Education Branch, I worked closely with the Premier's Council and know that it is highly regarded as an agent of support for the needs and interests of persons with disabilities. I have great respect for the work of Gary McPherson, Eric Boyd, Fran Vargo, Diane Earl and the others at the Council that I have worked with over the years.

I feel privileged to join the team and have been warmly welcomed by Gary and the office staff here. I know that I will learn and grow personally and professionally through this work, and I look forward to connecting with individuals, communities and organizations in order to ensure that what I do and say is truly representative of those the Council is intended to speak for. ♦

Status Report

Editor: Cliff Bridges

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Disability Coalition Picks Up Steam

In July, 25 provincial disability organizations, including CPA Alberta, met to identify common issues of concern. The goal was to determine key areas that government must address, during ongoing restructuring, to ensure equal opportunity for all citizens.

Further, the organizations realized they needed to unify as a coalition and present the issues with one powerful voice at the recently held Growth Summit Conference.

The coalition determined that three issues were paramount: investing in all Albertans, fostering a vision of a caring society, and addressing fragmented services and regional disparities. Further, it was decided that these issues affect more than just Albertans with disabilities; they affect virtually all disadvantaged citizens of our province.

The issue of investing in all Albertans is based on the fact that a primary goal of government policy is to encourage competitiveness of communities and individuals.

However, Albertans with disabilities have historically rarely been viewed as potential competitors and producers. The Coalition believes government must develop policies, programs and attitudes that promote self-sufficiency of Albertans, and that the provision of necessary supports to Albertans with disabilities is viewed as an investment with real, tangible returns.

The issue of fostering a vision of a caring society evolves from the threat of business and economic interests being pursued to the exclusion of social issues. In articulating this issue, the Coalition has suggested that social issues—poverty, illiteracy and discrimination—are linked to economic prosperity, and that government must extend assistance to its citizens to ensure growth is balanced and of a long-term nature.

The issue of fragmented services and regional disparities has long been a concern to Coalition members, and much more of a concern since restructuring began. The Coa-

lition maintains that services—accessible transportation, healthcare, and supports—must be consistent across the province in order for Albertans with disabilities to have the same opportunities for independence and to make contributions, no matter where they live in the province.

As such, the Coalition recommends that government, business and regional authorities take an active role in implementing and maintaining core standards of service delivery.

These issues were carefully crafted in detail into a discussion paper, which was presented to participants at the Growth Summit Conference. Participants were asked to respond during or after the Conference to the paper.

For more information, or to obtain a copy of the discussion paper, contact the Coalition of Provincial Disability Organizations, c/o 9357 - 98A Street, Edmonton, Alberta T6E 3N3 Fax: 403/439-3124. ♦

Survey finds caregiving on the rise; caregivers are at risk

A recently completed StatsCan survey has found that caregiving by family members is on the rise, and that the commitment of providing care is taking its toll on caregivers.

The 1996 General Social Survey found that more than 13 percent of all Canadian adults—some 2.8 million people—are providing care to someone with chronic health problems or disabilities. Of these, about two-thirds are employed, and women are almost half again more likely than men to be caregivers.

In most cases, the person being provided care is an elderly parent, which corresponds to estimates of our rapidly aging population. In fact, the largest proportion of caregivers are themselves, at the age of 45-64, not far from the senior citizen category.

Canadians, it seems, are a compassionate lot. More than half of caregivers indicated they didn't feel burdened by their duties, and about 20 percent "nearly always felt" they should be doing more for those in charge.

The cost of caregiving, however, is high. About 20% of all caregivers said that their own health had been affected by carrying out their duties. More than 25% said that caregiving had affected their sleep patterns and had created stress. Of those working as well as providing care, approximately half reported that the commitment was affecting their jobs—arriving late, leaving early, and taking days off were all reported as being necessary. Further, more than 40 percent of caregivers reported having to incur out-of-pocket expenses.

The messages are clear. Caregiving, as with the average age of our population, is on the rise. Those requiring care are increasingly likely to live in their own homes or in communities with their families.

This no doubt represents relief to governments reeling from escalating costs in the long-term care field. But the costs to individuals providing care are heavy, and must obviously be considered during any discussion of long-term, homecare types of policy and program development. ♦



Aboriginal Advocacy Pays Dividends

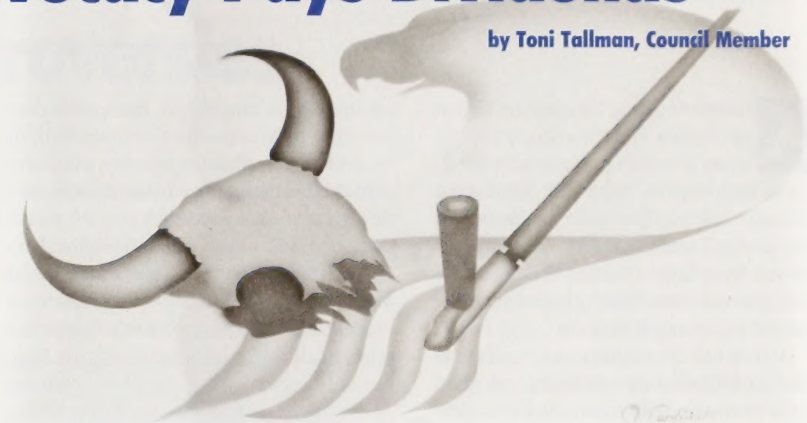
by Toni Tallman, Council Member

In Alberta and throughout Canada, Aboriginal people with disabilities have been striving for self-determination. They are anxious to show that, given the right conditions, they can develop lives of independent choice and action.

Independence and freedom are cornerstones of the Canadian way of life. Our country was founded upon these principles, which are enshrined in the Charter of Rights and Freedoms.

As Canadians, we value every person's right to shape their own destiny, and we make great sacrifices to guard and protect our freedom. Thus, to extend the concepts and philosophies of freedom and independence to the treatment of Aboriginal people with disabilities in our society would seem logical.

However, when we examine the status of Aboriginal people with disabilities, and particularly when we look back into the past, we discover certain attitudes and practices that are based on anything but the concepts



of freedom and independence. We find that Aboriginal people with disabilities have been thought of and treated as helpless children, patronized and denied access to knowledge, information, resources, training and shelter. They have seldom been given a chance to speak on their own behalf. They have been segregated, placed in boarding and residential schools and institutionalized—and this continues to this day. They have been discriminated against, both intentionally and unintentionally, and they have been deprived of certain rights.

Some Aboriginal people have been forced to stay at home and live with their families long after becoming adults because the services needed for independent living weren't available. For similar reasons, some people have been forced to live in institutions where they are given few choices about what they eat, what to wear, and when to go to bed. Even those who have overcome basic barriers to independence have discovered that they still can't benefit from many of their community's facilities and services.

It has been traditionally accepted by the public that Aboriginal people with disabilities are passive, submissive and unable to participate in making decisions that affect their lives. In addition, it has been generally accepted that they are more vulnerable to overprotection and paternalistic attitudes.

Every person in our society has the right to live life to the fullest. However, many people with disabilities face barriers that

prevent them from doing so. Perhaps they are denied access to public facilities, transportation systems, or to services and programs they need to live independently. These barriers can be in the form of physical inaccessibility, or self-imposed barriers that are the result of poor self-esteem. Whatever the reason for the barrier, advocacy—the process of speaking out in support of a person or an issue—can help.

Advocacy is a vital resource and an essential tool for anyone wanting to bring about change. In recent years, we have witnessed a heightened awareness of individual rights and a growing recognition of the political power that well-organized disability organizations can yield. Such groups have become a vital force for self improvement and social change, both on and off reserve.

I have become aware of many Aboriginal organizations within Alberta that are attempting to improve the lives of Aboriginal children and adults with disabilities through service provision and advocacy.

I need to tell these groups that their voices are being heard. I recognize that their task isn't an easy one—but with continued advocacy and lobbying efforts, decision-makers will increasingly include disability issues and concerns as priorities within our communities.

You are catalyzing much-needed change that is required to provide a brighter future for Aboriginal people with disabilities and their families and caregivers. ♦

Aboriginal Hospital Representatives Available in Calgary

The Calgary Regional Health Authority has taken a positive step forward to ensure Aboriginal hospital patients are accommodated in a culturally-sensitive way.

The RHA has hired Aboriginal representatives at the Rockyview, Peter Lougheed and Foothills Hospitals to better meet the needs of Aboriginal patients.

These representatives meet with patients and link them with community resources. They can be reached by contacting the Social Work Department at each hospital from 8:00 a.m. to 4:30 p.m., Monday to Friday. Each representative carries a pager.



Atlanta's "Visitability" Ordinance

by Cliff Bridges

Atlanta may have bungled the Olympic Games. But it's a champion city when it comes to home accessibility. In fact, Atlanta is the only city in the United States that has adopted a "visitability" ordinance. The ordinance requires a basic level of access in new single-family homes that are being built with some form of government incentive.

Atlanta has this ordinance because of the efforts of Eleanor Smith. Smith, who had polio, runs an organization called Concrete Change. The seeds for the visitability ordinance were planted in the late 1980s when Smith toured houses built by Habitat for Humanity, the non-profit organization that builds for the poor. None were accessible—and that didn't sit right with Smith.

She convinced the Atlanta office of Habitat for Humanity to include basic accessibility in its homes. From there, she found an ally—an Atlanta councilwoman whose daughter uses a wheelchair. The councilwoman introduced the ordinance, which was quickly passed in 1993. There have been problems with lack of enforcement, but those have largely been solved since a new chief building inspector was hired.

The result? Drive through an Atlanta neighbourhood and you're likely to see one of the 600 to 1,000 houses that have been built in compliance to the ordinance. They

are in all price ranges and, more often than not, aren't obvious—they've been built in an aesthetically pleasing manner, with carefully crafted ramps often being the only subtle sign of their accessibility.

Specifically, the ordinance requires one flat or sloped entrance, doors at least 32 inches wide, wall switches and outlets at reachable heights, and reinforced bathroom walls to allow for installation of grab bars. Not only does this mean that new houses are "visitabile" by someone using a wheelchair, it means that most wheelchair users could move right in without serious modifications.

"We relied on our lives and also what we thought would fly," says Smith. "Some people pressed us to go for a lot more features. One of the mistakes that I've seen when people try to press for access is to imply that if you don't have the whole laundry list of 29 or 40 items, you might as well not do anything. We knew it would not pass if we went for a lot more features—if it significantly raised the price of the house."

What's the price of complying with the ordinance? "It's ridiculously low," says Smith, quoting figures of zero to \$200. "Anyone who tries to do it right and use their common sense can do this for very little money. It has to be acknowledged that there are lots where a no-step entrance is impossible. But there are very few."

For five years, Smith has expanded her efforts in the hopes of having a state-wide visitability bill passed in Georgia. Each time it's been introduced, the bill has failed. Likewise, a similar bill in the state of Illinois recently failed to make it through the legislature. Why the problem, if compliance is both simple and inexpensive?

The roadblock, according to Smith, is the result of a powerful lobby effort put forth by the National Association of Home Builders. "For the first couple of years, they used cost figures. Finally, we were able to refute those cost figures. Now they use the rationale that it shouldn't be mandated—a person's house is their castle and they should be able to do what they want. I even started to wonder, 'Gee—is it so simple that they just want to charge the brand new home buyer \$3,000 to do the change order? Is that what they want—to keep it a big, hairy deal so that when someone requests it, they can charge more?'"

Smith admits occasionally giving into frustration, but this year, she's having the bill reintroduced—and is determined to continue doing so until it becomes law.

Alberta home builders aren't required to incorporate any level of accessibility—and most don't, save for a handful of builders who either have a social conscience or have recognized the potential to profit from such housing. The situation is likely to remain the same, unless an Albertan version of Eleanor Smith or a champion at the decision-making level pops out of the woodwork.

For Smith, pursuing the elusive goal of having accessible housing built as a matter of course is a mission—and she'd like nothing more than others to share it with her, even on Canadian soil. Her organization, Concrete Change, has produced an information kit of common sense "visitability" suggestions and practical advice for advocates to pursue legislative reform.

The Premier's Council has one of these kits. For more information, or a copy of the kit, give our office a call at 800/272-8841. ♦

Fashion Statement

A new Canadian company specializes in sporty, stylish clothing that is specially proportioned for wheelchair users. Offerings include cargo pants and shorts, anoraks, leggings, pullovers and mitts. Fabrics are high quality, breathable and easy to care for. All garments are easy to don and adjust, thanks to numerous zippers, loop pulls and Velcro fasteners.

Prices start at \$45. Sizes range from extra small to extra large. For a free Kymotion Designs brochure catalogue, call 416/651-6911. ♦





Sweden, Vatican at Centre of Eugenics Controversies

Alberta's woes over forced sterilization are small-scale compared to the recently-surfaced scandal in Sweden.

In August, the country was rocked by the revelation that Swedish governments practiced a Nazi-like campaign of forced sterilization, with up to 60,000 women having been subjected to the procedure in a period beginning in 1935 and continuing until 1976.

The revelations were unveiled by journalist Maciej Zaremba. Zaremba claims that Sweden, Norway and Denmark pioneered racial cleansing "sciences" after WWI, and that the sterilizations in Sweden were designed to rid the country of inferior racial types and to encourage Aryan features.

The sterilizations were officially labelled as voluntary. But those subjected to the procedure say they were ordered to sign permission slips or risk losing children and benefits.

Sweden's social affairs minister, Margot Wallstrom, called the sterilizations "nothing but barbaric." She has promised to raise the subject in cabinet. Whatever the case, the door is now certainly open for thousands of legal claims for compensation.

Meanwhile, an international disability organization claims that the Catholic church

continues to promote abstinence and sterilization for people with disabilities.

Disability Awareness in Action is a newsletter funded in part by the British Government and published collaboratively by a number of groups, most notably Disabled

"...if disabled people are unable to abstain from sex, they should consider sterilization."

Peoples' International. In the August 97 issue of the newsletter, a front page story claims that Bishop Javier Echevarria, head of the influential Catholic organization Opus Dei, said earlier this year that most disabled people are the offspring of "impure parents" who had sexual relations before marriage.

The article further claims that "the Vatican and its arms continue to suggest that disabled people should abstain from sex to ensure they do not "infect" partners or produce disabled children." Specifically, it is reported that Maria Cristina Baldicci, a sur-

geon at the University of the Sacred Heart in Rome, wrote in a journal article that disabled people should "collaborate with God to avoid creating further pain and sorrow" by sublimating their sexual urges into "friendship, or something more transcendental".

In defending her report, Dr. Baldicci said it was "fully in line with the teaching of the Church"; if disabled people are unable to abstain from sex, they should consider sterilization.

Apparently, Baldicci's statements were given qualified support from the semi-official mouthpiece of the Vatican, *L'Osservatore Romano*, which only added that abstinence "cannot be imposed either by the State or by doctors".

The newsletter's front page concludes by suggesting these attitudes, in addition to being clearly eugenicist in nature, fly directly in the face of the United Nations Standard Rule 9: "States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood." ♦

Disability on the Airwaves

He's the disability movement's answer to Howard Stern. Well, not quite. But Greg Smith, a wheelchair-using African-American who has muscular dystrophy, doesn't pull any punches when it comes to the rights of people with disabilities.

Smith's syndicated radio show, *On A Roll*, which is carried in many major markets throughout the United States, zeroes in on various controversial disability issues, including eugenics, the Americans with Disabilities Act, sexuality and much more.

Listeners who strongly agree—or disagree—with the opinions they hear can call in and participate.

On a Roll often focuses American themes, but Canadian listeners with an interest in disability will find it interesting, entertaining, and sometimes outrageous. *On a Roll* is broadcast each Sunday at 5 PM (7 PM eastern time). All you need to tune in is a computer with Internet capability and a sound card—set your browser to www.onarollradio.com, select "Listen to On a Roll On Demand", and follow the instructions on your screen. ♦



New Disability Research Projects

The federal government is funding six new research projects aimed at enhancing economic and social participation of Canadians with disabilities.

These projects are being funded through a joint program of the Office of Disability Issues (Human Resources Development Canada) and the Social Sciences and Humanities Research Council of Canada. This program, developed in 1993, funds research projects with the broad goal of acquiring a better understanding of circumstances that lead to greater integration of persons with disabilities in Canadian Society.

The six new projects are all at least two years in duration. They involve a total of 22 researchers from 12 Canadian universities working in partnership with some 36 community organizations and social service agencies in several regions of Canada.

An Alberta project, entitled *Employment Support for Disabled Persons: Policy and Outcomes*, is being led by prominent University of Calgary educational psychology professor Aldred Neufeldt. The project is timely given that programs that encourage employers to hire and train people with disabilities, as well as programs that encourage people with disabilities to consider self-employment, are gaining popularity across Canada. Neufeldt will attempt to pinpoint the benefits and effectiveness of such programs and their various components.

A related project, entitled *Successful Work Entry for Persons with Disabilities: Workplace Perspectives*, will take place at McMaster University. This study, involving a variety of businesses, government and not-for-profit agencies committed to hiring persons with disabilities, will strive to determine what's required in order for persons with disabilities to successfully enter or reenter the workforce. This project is being led by health sciences professor Muriel Westmoreland.

A team of researchers in Saskatchewan, led by University of Regina social work professor Douglas Durst, will study the plight

of First Nations people with disabilities living off reserve. Titled *Urban First Nations People with Disabilities: Triple Jeopardy*, this study will attempt to identify practical solutions for overcoming the major barriers experienced by the target group. These barriers include personal barriers arising from discrimination, lack of culturally-sensitive urban social services, and institutional practices that hinder access to programs and services that are supposed to be open to the general population without preference.

Factors Facilitating the Integration of Hearing-Impaired Adolescents: Implications for Policy and Practice is a study recognizing the increasing number of students with hearing impairments who are being educated in regular classrooms. This study will examine how successful integration is achieved and the barriers that work against it. The project leaders are University of Ottawa health sciences professor Andrée Durieux-Smith, who is an audiologist, and Dr. Janet Olds, a psychologist with the Children's Hospital of Eastern Ontario.

A Victoria, B.C.-based study will attempt to quantify the knowledge and experience of persons with disabilities concerning their

health care. This three year study, titled *Project Inter-Seed: Learning from the Health Care Experiences of Persons with Disabilities*, is being led by Marie Campbell, professor of human and social development at the University of Victoria. In collaboration with consumers and health care professionals, Campbell will explore the health care needs of people with disabilities so that they may be provided for in a manner that promotes greater independence.

The final project is titled *Taking Action for the Integration of Persons with Disabilities: Assessing Implementation of the United Nations' Standard Rules*. The United Nations' Standard Rule on the Equalization of Opportunities for Persons with Disabilities provide a framework for the development of policies that improve opportunity for persons with disabilities throughout the world. How Canada's various levels of government have implemented the rules is the subject of this study by University of Winnipeg political science professor Deborah Stienstra and private scholar Patrick Kellerman.

These six most recently funded projects bring the total number of projects to have received funding under the program to 24. ♦

Technology Teaches Speech to Deaf Kids

While it remains a controversial issue, an increasing number of deaf and hearing impaired children are being taught in the regular classroom. A problem educators have encountered is the difficulty in teaching deaf kids to speak when they don't know what speech is supposed to sound like.

IBM's answer is the SpeechViewer III, which combines special software and PC technology to show kids what speech looks like on a computer screen so they can make sounds that match the image they see. IBM says the device is great for use with children who are deaf, hard-of-hearing, or autistic, and is proving to be an extremely valuable tool for speech pathologists, teachers and other rehabilitation professionals.

SpeechViewer III sells for \$1399 and comes packaged with software and a microphone. It requires at least a 486-50 PC operating with Windows or OS/2, a Soundblaster or Mwave sound card, a CD-ROM drive and an SVGA monitor.

For more information, check out the IBM special needs website (<http://www.can.ibm.com/specialneeds>). ♦



Job Program Targets Quadriplegia

The Alberta division of the Canadian Paraplegic Association (CPA) and EmployAbilities, an Edmonton-based employment agency for people with disabilities, have launched a two year initiative designed to assist people with quadriplegia find employment.

Quadriplegia is not exclusive to individuals with spinal cord injuries, but also includes individuals who are quadriplegic as a result of multiple sclerosis, cerebral palsy and muscular dystrophy.

The Community Employment Supports Pilot Project (CESPP) is based on CPA's National Employment Survey, which found that a disproportionate number of quadriplegics were unemployed.

The project's developers believe many of these people are discouraged and give up on employment as a viable goal, and have decided to test these assumptions and use the results to influence the redevelopment of service delivery systems.

The target group is people with quadriplegia receiving Assured Income for the Severely Handicapped (AISH). CPA is preparing promotional material for distribution to all individuals with quadriplegia who are receiving AISH benefits.

It has been agreed that all participants should come to the program voluntarily without fear of losing their existing benefits and with an interest in developing vocational opportunities that will allow them to contribute to the communities of their choice. To ensure this, CPA, EmployAbilities and the Director of the AISH program will jointly prepare a letter ensuring participants that they will not lose their medical or AISH benefits if their efforts on the CESPP are not successful.

CPA and EmployAbilities will be responsible for informing all stakeholders, includ-

ing front-line workers in government and community service delivery programs, about details of the project.

Participants will be provided access to necessary disability-related supports (many are now in place through Alberta Advanced Education and Career Development, Alberta Community Development and Human Re-

source Development Canada). They will also have access to subsidized health care benefits during transition, as well as access to hiring incentives (CPA Alberta).

CPA vocational rehabilitation counsellors will complete an intake interview to identify unmet needs and complete a referral to engage CPA's vocational rehabilitation counsellors.

CPA community rehabilitation counsellors will assist the client in assessing his/her vocational potential and, where appropriate, develop an Individual Written Rehabilitation Plan (IWRP) with supporting documentation outlining vocational goal, training, education, and other supports required, with timelines and costs. The plan must be signed off by the client/consumer.

The vocational rehabilitation counsellor will also provide case management assistance in obtaining the necessary income and disability-related supports that are required. This same counsellor will engage the services of CPA community rehabilitation counselling personnel, vocational evaluators, job developers, and other external resources that can be provided and managed concurrently.

CPA vocational evaluators will complete a vocational evaluation to assess vocational potential and job matching strategies. Finally, a referral will be made to CPA/EmployAbilities job developers when the individual is ready to begin the job search. Ultimately, the pilot will be evaluated. Dr. Aldred Neufeldt of the Rehabilitation Studies Program at the University of Calgary and Dana McKie, a second year graduate student from the Rehabilitation Studies Program, will help design and conduct the evaluation of the project.

Goals of the evaluation are to:

- identify incentives that encourage participation and influence results.
- report on the number of people who participated, completed plans, went on to training, and ended up employed.
- determine approximate direct savings to income support programs and apparent economic contributions made by those employed.
- determine the average duration and costs of providing services (utilize CPA's electronic case management system).
- comment on the lessons to offer improvements to service delivery systems.

If you're a quadriplegic currently using AISH, and are interested in pursuing a career or vocation, this is your opportunity. Contact your local CPA office for information about how to get involved. ♦



CPA and EmployAbilities say that a disproportionate number of quadriplegics are employed—and are taking steps to correct the problem.



Preserving Your Child's Inheritance with a Henson Trust

by Kenneth C. Pope

Jason had been in and out of psychiatric hospitals for much of his adult life. Sometimes he would be balanced and able to work for months. Then he would slip into a severe depression. At the age of 35, Jason was diagnosed with manic depression.

Although still fit, Jason's parents worried about what would happen once their only child didn't have them to depend on any longer—emotionally or financially. They wanted to make a provision in their will that would do as much as possible for Jason.

But parents who have a child with special needs face a dilemma other parents never have to deal with: without special arrangements, any inheritance they leave as an asset in their child's hands will be offset against any social assistance that he or she receives.

Some parents have tried to create their own options to protect the inheritance. For example, they place the money in the hands of a trusted family member or friend, in a "secret trust". Such an arrangement leaves the beneficiary with no recourse if the trustee goes bankrupt or loses the money through divorce or bad financial management. And, if the arrangement is discovered, the province can take legal action to obtain access to the money on behalf of the person with a disability to offset support payments.

But there are two legal solutions to this problem, neither of which is generally well known.

The first recourse is necessary if no planning has gone into the parent's will. A special disability trust is set up with provincial approval and monitoring (in Ontario it would be under Family Benefit Allowance, or FBA), when no provision is made in the parent's will. This is a partial solution, and better than losing the entire inheritance.

The second, called a Henson trust, is created by the parent's will. It is the best av-

enue to parents of children with disabilities. This absolute discretionary trust places estate assets in the hands of a trustee, selected by the parent, who administers it for the beneficiary.

In both cases, the trustee can disburse funds from the trust for disability-related support and services for the recipient, just as the parents could while they were alive. In addition, a beneficiary can receive small comforts such as spending money, a radio,

"By being explicit and including the trust in their will, parents can ensure that their wishes will be respected, no matter what happens later."

record player or television set, personal clothing, extra food, recreation, entertainment and vacations.

Although the Henson trust is Ontario case law, people in other provinces should use the same form of trust because it will be at the least persuasive in their own province, and would be very likely to be upheld if brought to their own provincial court for interpretation.

Compared to a Henson trust, there are clear disadvantages of an FBA trust:

- While the FBA trust is presently allowed (since 1993), it could quickly be removed by a change to the regulations of the FBA. In Ontario, a review of allowable disabilities and social support payments is now going on.
- The FBA trust is created by the beneficiary who receives the inheritance, with Ministry approval, rather than by the par-

ents in their will. Depending on the abilities and competency of the beneficiary, this may pose problems.

- The FBA trust is limited to \$65,000, which may be less than the estate left to the child. The remainder is used to offset FBA directly until it is all gone. This limit may be increased at some time, but this will likely go hand-in-hand with a requirement that more of the estate money be used to offset FBA payments.
- The FBA trust fund is intended to be exhausted during the beneficiary's lifetime. Funds left in a Henson trust are generally left to the siblings or children of the beneficiary when he or she dies.
- Income earned by the funds in an FBA trust that are not paid out to the beneficiary are deemed to be received anyway, and offset against FBA payments. This does not happen with a Henson trust.
- Income in an FBA trust not paid out may be taxed at the maximum marginal rate (50%) on every dollar, while Henson trust income that accumulates is taxed at low and increasing marginal rates, like income for any other taxpayer.
- The costs and administration involved in setting up an FBA trust after the fact can easily be greater than the cost of simply planning properly in the first place, while a parent's will is being prepared.

For these reasons, it's important that Henson trust arrangements be made as part of estate planning at the time the will is drawn up. By being explicit and including the trust in their will, parents can ensure that their wishes will be respected, no matter what happens later.

The choice of trustee is a critical factor in making the plan work. The trustee should be someone who is financially capable, fair minded and who has the beneficiary's best interests at heart.

It is common for siblings to be appointed as trustees, although there is potential for conflict of interest. This can be resolved by appointing joint trustees, such as the combination of a sibling and a family friend. A plan for alternates as time goes by deals with the concern about a beneficiary outliving their trustee.

Before making a decision to incorporate a Henson trust into their wills, parents should review these key considerations:

- If their child is likely to be a permanent recipient of Family Benefits, will he or she have needs or wants beyond what will be received under this plan?
- What will be the size of the parents' estate, and the portion going to this child?
- What are the needs of other beneficiaries?
- Is the child likely to be disqualified from Family Benefits in future because he or she will be employed or because of legislative changes?

- Is there a possibility that the child will be considered dependent under the relevant legislation, even as an adult? If so, leaving the child out of the will entirely would invite an application to the courts for dependants' relief. This will tie up the whole estate and generate substantial legal costs. Such an action would almost certainly be successful, with the estate funds being paid into Court and administered by the Public Trustee and Guardian.

Specialized legal counsel is the best insurance that estate arrangements will give you peace of mind and a dependable plan that will work for the whole family. A lawyer who specializes in this field can properly advise you and make provision for such a trust in your will to plan for the ongoing needs of your child. ♦

Kenneth C. Pope is a barrister and solicitor practising in Ottawa, Ontario. He can be reached at 613/567-8230.

While FBA trusts relate directly to the Province of Ontario, Mr. Pope feels strongly that the Henson trust warrants consideration in Alberta. While certainly not binding in Alberta, it is based on standard common law principles governing trust law in Canada.

In addition to contacting specialized legal counsel for more information in this area, any government departments providing income support to an intended beneficiary, such as AISH, should be contacted for their interpretation of discretionary trust funds and how they may coexist within the boundaries of that specific program.

As well, given its role as the government-appointed body responsible for many dependent Albertans with disabilities, the office of the Public Trustee may also be a source of information. You can contact this office at 403/427-2744.

This article first appeared in Abilities magazine, Fall 1997.

Accessing the Doctor's Office

Rick Hansen can conquer the Great Wall of China but can he get into your office?

That's the question that appeared—along with a photo of the Man In Motion—on the cover of the March 1st, 1997, issue of the *Canadian Medical Association Journal*. The cover served to introduce a comprehensive article on medical office accessibility. The article was written by Drs. Karen Jones and Itamar Tamari, Toronto physicians who are very concerned that the medical profession has been unresponsive to the accessibility needs of people with disabilities.

"General practitioners are thought to have more contact with persons with disabilities than any other profession or agency," wrote the authors. "Nevertheless, many physicians' offices are inaccessible, and there is little information readily available to Canadian physicians who wish to improve the accessibility of their offices. Persons with disabilities who require medical care are therefore deterred from seeking it by the difficulties they encounter when visiting a physician."

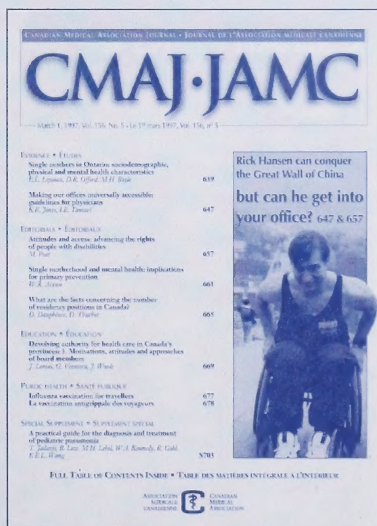
The article then goes on to provide an exhaustive list of guidelines for including specific accessibility features in and around a

medical office that often are beyond what's required by Canada's various building codes. These guidelines deal with getting to and entering a medical facility, entering offices and waiting rooms, access in restrooms, and improving access in the examination room. The guidelines are sensitive to all disabilities: physical, cognitive and sensory.

According to the authors, the article represents the first set of such guidelines that have been made available to Canadian physicians who wish to make their office-based practices more accessible.

The article's conclusion presents the author's rationale in providing such guidelines. "We believe that there are strong ethical and legal reasons to make our offices more accessible. Although economic barriers may prohibit physicians from making radical, immediate changes, and some changes may be very expensive, others cost little or nothing.

"There is evidence that future legislation may mandate full office accessibility; hence, starting to implement features of accessibility today may decrease the economic burden in the future and may also broaden the scope of our practices." ♦



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News and Notes

DATS Cancellations Up

Edmonton's Disabled Adult Transportation System (DATS) is experiencing a major upward trend of cancellations.

In 1995, 13% of all scheduled trips were cancelled. In 1996, this percentage jumped to 14.7%. As of February of this year, the cancellation rate was 19%—almost 15,000 of 78,900 booked trips. The result is a serious problem contributing to the system's inability to provide quality service to Edmontonians in a cost-efficient manner.

Since almost 75% of cancellations come in too late for anyone else to book the space, other DATS customers may not get their bookings or preferred time. These cancellations also cause longer waits on the telephone when booking, longer trips, delays in reaching destinations and, ultimately, higher costs and a reduction in the number of trips available to customers.

DATS allows for customer cancellations by overbooking the number of budgeted trips. The difficulty is that DATS doesn't know when the trips will be cancelled or by whom. This affects the drivers' ability to meet the schedule pick-up and drop-off time.

It's a reality that customers experience unforeseen events or changing plans that force cancellations. However, DATS says many customers are abusing the system. DATS attempts to deal with these customers individually, but adds it's important that all users understand the problem.

For more information, please call DATS administration at 496-4570 in Edmonton.

Winter Paralympic Update

The 7th Winter Paralympics, to be held in Nagano, Japan, are just around the corner.

Canada will be sending a team of 50 to 55 athletes and staff to the event, which takes place from March 5th to 14th, 1998. The best Paralympic athletes from around the



photo courtesy Rick Hansen Centre

Cross country skiing—one of the Winter Paralympic's featured events

world will be vying for gold in five winter sports: alpine skiing, biathlon, cross country, ice sledge racing and sledge hockey.

The Winter Paralympics include athletes

who are visually impaired, paraplegic and quadriplegic, have cerebral palsy, and are amputees. Additionally, athletes with developmental disabilities will compete in cross country events. In total, over 1,000 athletes from 30 countries will compete.

Former Paralympic athlete Patrick Jarvis of Calgary has been selected as Chef de mission for the Canadian Team. Jarvis, a competitor in both summer and winter Paralympics, has completed his inspection of the facilities in Nagano. He reports that the venues will be "excellent for the Games."

The Nagano Games mark the first time the Winter Paralympic Games have been held outside of Europe. Additionally, it's also only the third time since inception in 1976 that the Games have been held in the same city as the Olympic Winter Games.

For more information on the 1998 Winter Paralympic Games, contact the Canadian Paralympic Committee in Ottawa at 613/748-5630 or check out the Nagano Paralympic website (<http://www.nagano.paralympic.org/>). ♦

Coming Events

Capital Regional Health Authority and the Community Care and Public Health Division present the 2nd Annual Designing Community Health Conference. November 19 to 21, 1997, at the Fantasyland Hotel in Edmonton. Theme: exploring the health reform process with emphasis on health promotion, disease prevention and community participation. Speakers include Halvar Jonson, Minister of Health. Contact: Margaret Buhay, conference secretary, at 492-2080. ♦

Is your association or agency sponsoring a provincial or national conference or workshop? If so, please forward the pertinent information to:

The Premier's Council on the Status of Persons with Disabilities

#250, 11044 - 82 Avenue Edmonton, Alberta T6G 0T2

Tel: 422-1095 (Edmonton)

or 1-800-272-8841 (rest of Alberta)

Fax: 403/422-9691

E-mail: pcspd@planet.eon.net

